Preparing for a Lung Transplant
Welcome to the Lung Transplant Program

The Ohio State Comprehensive Transplant Center’s doctors and staff welcome you as a possible lung transplant candidate.

As you begin this journey, you and your family may have many questions and concerns. We hope that this book will help you learn about the process for lung transplant, so you know what to expect.

The goal of a transplant is to allow you to live a more normal life, but there are changes you will need to make after transplant to have the best outcome.

If you have any questions or concerns, please talk to your lung specialist or contact the Comprehensive Transplant Center at 1-866-204-3411 or 614-293-5822.

Why do I need a lung transplant?

Several medical conditions may lead to lung transplantation as a treatment option, such as:

- Alpha-1 antitrypsin deficiency
- Bronchiectasis
- Bronchiolitis obliterans
- Chronic obstructive pulmonary disease (COPD)
- Cystic fibrosis
- Eisenmengers physiology
- Emphysema
- Lymphangioleiomyomatosis (LAM)
- Primary pulmonary hypertension
- Pulmonary fibrosis
- Pulmonary hemosiderosis
- Sarcoidosis
- Systemic lupus erythematosus

Some patients may require one lung to be transplanted, while others may require both lungs to be transplanted.

There are several benefits as well as commitments that come with having a lung transplant. Your transplant team will discuss these with you, based on your current condition.
# Starting the Transplant Process

We strongly encourage you to have a support person attend all of your office visits, testing appointments, and education sessions with you. Because of your lung disease, you may have problems remembering and thinking, so your support person can be a second set of eyes and ears to help you.

## Transplant process steps

The journey through the process of organ transplant requires several steps.

- Referral for transplant
- Testing and evaluation
- Transplant education
- Selection committee decision
- Waiting list
- Getting the call
- Transplant surgery
- Living with the transplant

We will review each of these steps to help you know what you can expect. Please ask any questions you may have and let us know if there is anything that you do not understand.

## Referral for transplant

Your doctor may have talked to you about having a lung transplant because of the amount of damage you have to your lung. You will have a day of testing to evaluate the severity of your disease. Once you have completed your testing, you will be seen by a transplant pulmonologist, a doctor who treats lung disease patients. This doctor will review your records, explain the results of your testing, and discuss with you whether transplant is a good treatment option for you.

## Testing

You will be scheduled to have tests done to check your current health and whether you would be able to have transplant surgery. These tests will be scheduled at Ohio State Wexner Medical Center, or you may be able to have some of the testing done at your primary care doctor’s office or local lab.

Tests may include:

- Chest imaging including CT and lung perfusion scan
- Blood tests
- Electrocardiogram (EKG or ECG) to check your heart beat patterns
- Cardiac echo to check the pressures in your heart and lungs and the blood flow through your heart
- Pulmonary function testing to check how well your lungs are working
- Arterial blood gas (ABG) to check oxygen levels in your blood
- 6-minute walk test to check your heart and lungs when you are active
- Chest x-ray
- Cardiac catheterization to look at the blood flow through the heart and the blood pressure of your lungs
- Carotid duplex, an ultrasound of your neck to look at the blood supply to your brain
• Gastric emptying to look at the amount of food your stomach empties in a set amount of time
• Esophageal manometry and 24-hour pH probe to look at your esophagus and test for acid reflux
• Bone density to measure the strength of your bones
• Dental clearance (within 1 year)
• Cancer screening that may include:
  › Colonoscopy if older than 50 or younger if you have a family history of colon cancer
  › Mammogram for women over 40
  › PSA for men
  › PAP smear for women
Some of these tests will be scheduled before your initial evaluation with the transplant pulmonologist. Others will be scheduled after you are found to be a candidate for lung transplant.

Pulmonary rehabilitation
Pulmonary rehabilitation is a requirement for lung transplant evaluation. It is an exercise program, which increases your strength and helps your muscles use oxygen more effectively. The therapists can also help you with breathing techniques to help manage your shortness of breath.

Evaluation day
When all of the results of your testing are in, you will be scheduled for an evaluation day. It may take up to 4 hours for this appointment.
• Bring a snack and something to drink with you.
• You are also expected to bring at least 1 support person with you to this appointment.

During the evaluation
After the first appointment, if the doctor feels like you are a good candidate for transplant, you will be scheduled for appointments with the following people:
• Dietitian to review your current diet and nutrition status and create a plan to keep you healthy. Changes to cooking and food prep and use of nutrition supplements may be discussed.
• Social worker to check your living situation, mental health, social support system, work history, and any issues with drug or alcohol abuse. Based on this review, you may also need to meet with the transplant psychologist. You must have a support person with you for these appointments.
• Pre-transplant coordinator will be your main point of contact. The coordinator will assist you through the entire evaluation process.
• Surgeon will talk with you about the plan for lung transplant and review the results of your tests. You will have a physical exam and the risks and benefits of the surgery will be reviewed with you.
• Financial coordinator will talk about your health insurance benefits and other financial resources, including your income and savings. We will help you create a financial plan to cover the cost of the transplant and follow up care, as needed.

You may be required to see these other doctors based on your testing:
• Cardiologist (heart specialist) will review the results of some of your test to determine if you have any heart issues.
• Infectious disease doctor will review your vaccination history and recommend vaccines that may be needed before transplant.
Transplant psychologist will work with you, if needed, to be sure you have the support and coping skills to handle the stress of the transplant process, or to coordinate alcohol or drug counseling.

Based on the findings from your evaluation, you may need other tests, or you may be given other guidelines that you need to meet before your case is able to proceed to the committee review process.

If your evaluation is complete, your case will be presented to the Patient Selection Committee.

Alcohol, drug and nicotine use
Alcohol, illegal drug, and nicotine use is strictly prohibited.

- If you drink alcohol or use drugs, you will be sent for counseling and 3 months of treatment to help you meet requirements for the transplant waiting list.
- If you test positive for nicotine, you cannot be on the lung transplant list for 6 months.
- If you are on the lung transplant waiting list and you test positive for alcohol, illegal drugs, or nicotine you will be placed on an inactive status or you may be removed from the waiting list.
- Random drug and alcohol screening is done for all lung transplant patients. If you are called to have drug or alcohol screening, you have 24 hours to complete the needed test, or it will be assumed that your results are positive and actions will be taken.

Transplant education
People considering transplant and their support person(s) are required to attend this class before being presented to Patient Selection Committee and going on the lung transplant list. There is much to think about before an organ transplant. The class is scheduled through the transplant center office by your pre-transplant coordinator.

Patient selection committee (PSC) review
This committee meets weekly to review new patients and to discuss updates for those patients who are either on the transplant waiting list or are waiting to be placed on the list. Many members of the transplant team are on the committee. As a group, they determine if you are a good candidate for transplant or if there are other treatment options for your care.

All aspects of your health, testing, and evaluations will be discussed and a decision will be made about your case. There are 3 possible decisions:
- You are an acceptable candidate.
- We require more testing to decide whether it is safe for you to have a transplant.
- You are not a candidate at this time. This may be a permanent or temporary decision. Continue your care with your lung specialist doctor.

The pre-transplant coordinator will contact you to let you know the decision from PSC about your case.

If you are an acceptable candidate, the transplant center will work to get your insurance approval for the surgery. They will also contact OSOTC (Ohio Solid Organ Transplant Consortium) to get approval to have you added to the lung transplant waiting list.
Placement on the waiting list

You will receive a letter and a phone call when you have been placed on the lung transplant waiting list.

There are several factors that determine your rank or placement on the waiting list that will be explained below:

- Blood type
- Height range
- LAS score

Blood type

There are 4 blood groups on the list: A, AB, B, and O.

- O and A are the most common blood types and have a longer waiting list, but they also have more donors available.
- AB and B groups have shorter lists, but there are fewer donors in these groups.

Height range

The donor lung size can determine which recipient is selected. Each patient on the waiting list will have a height range based on their body size.

LAS (Lung Allocation Score)

Lung Allocation Score (LAS) is a useful tool for both you and your healthcare team as you plan for a transplant. It is a numbered scale that estimates how well your lungs are working.

The scores range from 0, which means the lungs are working well, to 100, which means the lungs are working poorly and the person needs an urgent transplant.

The number is calculated by a formula that includes:

- A number based on your lung disease
- The results of your pulmonary function tests
- The results of your 6-minute walk test
- Blood test reports for your kidney and liver function
- Measure of your arterial blood gases (ABG)
- Measure of the blood pressure of your lungs

Testing will be done no less than every 3 months while you are waiting on the lung transplant list. This is both to monitor your lung disease and maintain an accurate LAS score. You may need testing more often based on the type and severity of your lung disease.
While waiting

Make sure that you are available by phone, check your messages, and respond right away. If we contact you for lung transplant and have to leave a voice mail message, you need to return the call within 1 hour to determine if you are well enough for transplant.

If you do not return the phone call in that time, the coordinator will contact the next person on the transplant waiting list, and you will miss the opportunity.

- Be sure to stay in close contact with your transplant coordinator. Let the coordinator know right away if you have:
  - Changes in your health, especially if you are seen in a hospital outside of Ohio State Wexner Medical Center.
  - Changes to any of your medicines.
  - Changes to your contact information or your family contact information if you listed them as a contact for you.
  - Plans to leave the state on vacation or for other reasons. You may be placed on Hold if you are out of range.
  - Any changes to your support system or caregiver plan
  - Any changes in your insurance.

- Have plans ready for child and pet care, if needed.
- Have transportation arranged, so you are ready if you get a call for transplant.
- You are expected to abstain from using drugs, alcohol, and nicotine while you are on the transplant waiting list and for life. You may be required to get random drug screening done while you are on the transplant waiting list.
- You will need to have ongoing lab work.
- You also need to have yearly dental exams, heart testing, other imaging tests, and keep all cancer screening current.
- Be sure to keep all of your appointments with your primary care doctor and lung specialist and have your needed lab work completed.

Contact the transplant team

Your transplant coordinator is available if you have any questions or concerns. All calls are routed to the coordinators and prioritized based on urgency. Calls are most often returned the same day.

If you have an emergency, do not drive yourself to the emergency room. If you go to the emergency room, please call or have a family member call the office at 614-293-5822. After hours, please ask to be put through to the nurse.
Getting the Call from the Coordinator

A transplant coordinator will call you when an organ is available.

- Organ offers come at all hours of the day and night. Be sure to keep your phone on at night.
- The phone number that the coordinator is calling from will not always show as an Ohio State number on your caller ID. Please do not screen calls as you may miss the call for an organ offer.
- You have 1 hour from the time the coordinator first called to return the phone call. You do not have to be at the hospital in an hour, but you do need to return the call.
- The coordinator will keep trying to call you and anyone listed as a contact for you during the hour.
- When the coordinator reaches you, you will need to provide information about any changes to your medical history, infections, fevers, and the distance you are away from the hospital.
- You may be asked to come to the hospital and then be sent home if the organ does not appear to be a good match for you or if the organ is poor quality. This would not change your position on the waiting list. You may also be sent home if you have an infection, test positive for drugs, alcohol, or nicotine, or you have a new health problem that would make surgery unsafe for you.
- Bring these items with you to the hospital:
  - Photo ID
  - Insurance card(s)
  - Current list of all medicines
  - Power of attorney or living will documents
  - Medical history and list of past surgeries
  - List of important phone numbers
  - Personal hygiene items
- Do not bring jewelry, large amounts of money, or other valuables.
- For the safety of all patients on the transplant unit, children age 12 or younger are not permitted to visit. Live plants, fresh fruits, and vegetables and fresh flowers are not permitted on the transplant unit.

Increased risk organ offers

You may be offered an organ that is considered to be increased risk, related to test results or behavior of the donor. The transplant team would only offer an organ that they feel would benefit you.

- The reason the organ is increased risk will not be shared with you when you get the call. The doctor would explain this more to you when you are admitted to the hospital for transplant.
- You would need to sign an additional consent after you talk to the doctors at the hospital.
Transplant Surgery and After Care

Possible risks or problems from surgery
The doctor will talk with you about risks and benefits of transplant surgery before you sign the consent form. There may be other risks, based on the donor organ and other factors. Ask questions if you do not understand the risks as the doctor explains them to you. The major risks include:

- Bleeding
- Infection
- Pneumonia
- Heart complications
- Blood clots
- Death

Surgery takes 4 to 12 hours
You will have general anesthesia, so you will not be awake through the surgery. The doctors will cut an incision based on the kind of lung transplant you are getting. You may get one or two lungs based on your lung disease, age, and your functional status.

You will have a breathing tube and several IV lines in place after the surgery is done. You will also have several drains in place for fluid to drain out and help with healing.

You will likely be on oxygen and a heart monitor after surgery. You will also wear sleeves on your legs that are connected to a pump, called a compression device or SCD. The compression device is used to prevent blood clots from forming in your legs while you are on limited activity.

Care after surgery
Most transplant patients spend a few days in the Intensive care unit. When you are able to breathe on your own, the breathing tube will be removed. You will then be transferred to the step-down unit to continue your recovery.

Most lung transplant patients will be in the hospital about 2 to 3 weeks. Staff will teach you and your support person about your care with an organ transplant, such as:

- Your medicines to prevent rejection of the transplant, also called immunosuppression medicines.
- How to prevent infections.
- How to care for your surgery incision.
- Problems that you should watch for and who to call.
Discharge planning

Your transplant team will determine when you are ready for discharge. Some patients need continued rehab and may be transferred to an inpatient rehab facility, such as Dodd Rehabilitation Hospital. Inpatient rehab allows patients to gain strength and participate in therapy to prepare them for life after transplant.

Any patient who lives farther than 30 miles from Ohio State Wexner Medical Center is required to stay locally at the time of discharge until released to home by the transplant team. The length of time you will stay locally is determined by your progress, healing and test results. Time spent at inpatient rehab or Dodd Rehabilitation Hospital does not count toward your time spent locally before going home.

You will be responsible for costs incurred to stay locally, including hotel reservations, food and transportation. Patients are encouraged to fundraise before transplant in order to afford these expenses. Sometimes apartments are available near the medical center at no cost. Availability of these apartments is not a guarantee and should not be your primary or only plan after discharge. In addition, you cannot stay alone until you are physically released to drive. This often occurs 6 to 8 weeks after your transplant, but may vary based on your condition.

Immunosuppression medicines, also called anti-rejection medicines

Your body’s immune system helps protect your body from infection and fights off things that might be harmful to you. After organ transplant, your immune system will know the transplanted lung(s) is not part of you, so it may try to fight against it. Immunosuppression medicines must be taken after a transplant to reduce your immune system’s ability to recognize the transplanted lung(s) as harmful. You will need to take these medicines 2 to 3 times each day, every day, for the rest of your life. As a transplant patient, you need to learn about your medicines and how to take them, including what side effects you may have.

You will need to have lab work done often to check the levels of your medicines to be sure they are in the right range to work best for you. You should never stop taking these medicines, or change the dose, without first checking with your transplant doctor.

- Doses will change frequently and you will need to communicate closely with your post-transplant coordinator to be sure you understand your instructions.
- **Only an Ohio State Wexner Medical Center transplant doctor** should be making changes to your transplant medicines.

Protect yourself from infections

Because these immunosuppression medicines weaken your body’s immune system, you need to take extra steps to stay healthy. You will be taught about how to protect yourself:

- Good hand washing.
- Wearing a mask.
- Avoiding others who are sick.
Post-Transplant Coordinator

Be sure to update your transplant coordinator with any changes in your condition. You can also call with any questions you may have regarding medicines, testing, restrictions, or anything that involves your health.

Appointments after transplant

You will have a number of appointments for follow up after surgery. Be sure to keep all of your appointments.

- You should plan to have appointments with your care team:
  - Twice a week x 1 month.
  - 1 time a week x 1 month.
  - Every 2 weeks x 1 month.
  - Each month x 9 months.

- Lab work:
  - Twice weekly for 8 weeks.
  - Weekly for 6 months.
  - Every 2 weeks for months 6 through 12.
  - Monthly after 1 year.

- Bronchoscopies:
  - On months 1, 3, 6, 9, 12.
  - None after the first year unless clinically indicated.

- You will also have spirometry every month for life.

Pulmonary rehabilitation

You will be expected to resume pulmonary rehabilitation after you are discharged from the hospital.

Contact with the donor family

This is your decision. Every donor family and situation is different. Some donor families want to share about their loved one while others find it too difficult.

Please call Lifeline of Ohio at 1-800-525-5667 to find out more about contacting your donor family.
What if Transplant Isn’t Right for Me?

Treatment options
There is no cure for end stage lung disease except lung transplant. If transplant is not for you for whatever reason, there are other treatments that may benefit you. Here is some information about possible treatment options. Talk to your lung doctor about treatments to manage your disease.

Pulmonary rehabilitation
• Prescribed exercise sessions that increase your strength and help your muscles use oxygen more effectively. The therapists can also help you with breathing techniques to help manage your shortness of breath.

Medical management
• Talk with your lung doctor to make sure that you are on the right medicines to manage your lung disease.

Palliative care
• Some patients decide that transplant is not right for them, and they want different goals in their treatment. Palliative care can help you determine what you want to do, and how you want to have your disease treated for the rest of your life. Do you want treatments to prolong your life, or do you want to be kept comfortable until your death? Palliative care can help you control your pain and ease your symptoms. Hospice services may also be useful to you and your family.
We want you and your family to learn about your care. Take notes and **write down your questions and concerns**, so you do not forget to ask. It is often hard to remember or you may feel rushed, so it can help to write your questions down. **If you do not understand something, please ask us to explain it in a different way.**